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# CONSUMER/SURVIVOR/RECOVERING WOMEN: A GUIDE FOR PARTNERSHIPS IN COLLABORATION

*Prepared for the Women, Co-Occurring Disorders and  
Violence Study Coordinating Center by*

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**November 2001**

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This publication was made possible by grant number 5 UD1 TI11404 from the Substance Abuse and Mental Health Services Administration's Center for Substance Abuse Treatment. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment, Center for Substance Abuse Prevention, and the Center for Mental Health Services.

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**Laura Prescott**

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– November 2001 –



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# Acknowledgements

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One of the most significant gifts I have received as a result of my involvement in the Women, Co-Occurring Disorders and Violence Study has been the opportunity to work with some truly extraordinary people. Even though there are far too many to name here, it is important to note their collective contributions to the ongoing dialogue regarding integration. Each consumer/survivor/recovering woman who stood up, spoke up, asked critical questions, and challenged assumptions reinforced the important nature of this new partnership endeavor. I'd like to thank them for their courage, tenacity and collective wisdom. In claiming and naming their experiences, they both honor the lives of women whose voices have been forever silenced and encourage those who still stand in the shadows. I hope this manual might be a tribute to them, their children and the allies who stand behind the scenes, pushing the agenda of inclusion forward, frequently without much recognition for their work. These are the women and men who believe in the dream of true collaboration, representation and integration.

This manual was developed in an attempt to offer additional insights into strategies, barriers and possibilities for creating a new vision of multicultural, gender-specific partnerships with women who have been traditionally considered "too vulnerable" to become integrally involved in "highly complicated" processes of research, evaluation and system/service design. It contains material that was originally written in partnership with Consumer/Survivor/Recovering women at the Women, Co-Occurring Disorders and Violence Coordinating Center: Jacki McKinney (Process and Outcome Evaluation Team); Ruta Mazelis (Knowledge Development and Application Team); and Mary Auslander (Technical Assistance Team). Ellen Bassuk and others at the Better Homes Fund, Pat Rieker and Elaine Carmen, and study consultants, were particularly helpful in further refining the concepts for presentation at a federal steering committee meeting in May 1999. These women have not only been friends and allies, but mentors as well.

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The collaborative work would not have been possible without support from Joseph Coccozza, Ph.D., Women, Co-Occurring Disorders and Violence Coordinating Center Director; Henry Steadman, Ph.D., President of Policy Research Associates, Inc.; and the federal project officers at the Substance Abuse and Mental Health Services Administration. In addition, the following people have generously provided their time, material, expertise and resources, frequently at the last minute, because they believed this manual needed to be written: Laura CinqMars; Jacqueline Prescott-Meyers; Pamela Davis; Darby Penney; Celia Brown; Andrea Blanch; and Jean Campbell.

This manual is dedicated to Dionne Smith and her children.

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## Introduction and Overview

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In 1998, the Women, Co-Occurring Disorders and Violence Study (referred to as the “WCDVS” or the “study”) was announced by the Substance Abuse and Mental Health Services Administration (SAMHSA) in partnership with its three centers: the Center for Substance Abuse Treatment (CSAT), the Center for Substance Abuse Prevention (CSAP), and the Center for Mental Health Services (CMHS). Preparation for this study by federal project officers confirmed earlier research findings documenting the extreme conditions facing Consumer/Survivor/Recovering (C/S/R) women and their children. This knowledge stressed the need to develop innovative and integrated treatment strategies that are gender-specific, culturally-sensitive and consumer/survivor-oriented. At the end of 1998, SAMHSA awarded grants to 14 study sites across the country and one to the Women, Co-Occurring Disorders and Violence Coordinating Center (referred to as “Coordinating Center”) at Policy Research Associates, Inc., in Delmar, New York (*original study sites listed in Appendix III*).

The goal of this new five-year initiative is to evaluate the impact of integrated and innovative service systems on women with co-occurring disorders who have histories of physical and/or sexual abuse and their dependent children. In addition, SAMHSA renewed its historical commitment to strengthening the involvement of C/S/R people within the goals of the study. In order to enhance the quality of the study design and efficacy of implementation, the sites and Coordinating Center had to demonstrate the level of C/S/R involvement and partnerships through all phases of design and delivery over the next five years.

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*“SAMHSA believes the development of partnerships among providers and consumer/recovering person groups is critical to the attainment of the goals of this study. Thus, activities that should become a part of the planning and implementation of all aspects of the study site designs include...those that create and maintain consumer/recovering person partnerships in designing and implementing the systems of care and service intervention models.” (SAMHSA, 1998, pp. 7–8)*

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Even in the early stages, this initiative reinforced the importance of productively integrating C/S/R women into its activities and provided many learning opportunities about accomplishing this important task. Over the last year, C/S/R women from the sites actively worked together building relationships with each other, our federal partners, the Coordinating Center and study site multi–stakeholder teams.

The lessons have not come easily, but they are powerful. Broad changes often begin with a certain amount of unanticipated chaos, and the ensuing miasma can be disconcerting. However, through ongoing dialogue, combined with a commitment to the values of inclusion, we have discovered that true partnerships can, and do, emerge. We have learned about the challenges and benefits of sharing power, negotiating language, and creating a common platform to move toward a united mission: That no woman impacted by substance abuse, violence, and mental health concerns remain invisible and voiceless in the shadows of fragmented services and systems.

## **Application of Lessons Learned to Broader Work Being Done in the Field**

The application of lessons derived from our experiences has the potential to provide the field with critical knowledge. In addition, these lessons create an extraordinary opportunity to strengthen partnerships among broad constituencies in the fields of mental health and substance abuse, domestic violence, child welfare, and criminal justice. The implications of our early work together resonate with significance, especially for programs addressing the complex and inter–related issues facing women and their children in a variety of service delivery systems.

## **Consumer/Survivor/Recovering Women: A Guide for New Partners in Collaboration**

The information presented in this document is a synthesis generated through individual and collective efforts to integrate C/S/R women at three levels: the 14 sites; the Coordinating Center; and the federal multi–site steering committee meetings, which convene approximately every three months. When possible, the qualitative data provided is supported by, and combined with, existing literature on the subject.

This guide does not represent a compendium of answers, but rather reflects recommendations based on current work being done in the field. We hope the ideas, strategies and recommendations in this document will be further refined for future application in programs committed to the principles of C/S/R integration.

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## The Goals of This Guide

The goals of this guide are to:

- Articulate a framework that distills the benefits and challenges of integrating C/S/R women into system, service and research activities;
- Enhance and promote dialogue about C/S/R integration efforts;
- Contribute to the current state of knowledge;
- Promote awareness of gender-specific and culturally-sensitive approaches that lead to successful involvement of C/S/R women in the design and implementation of services and research; and
- Provide recommendations that could facilitate the development of policy and practices that enhance opportunities for C/S/R women to become involved in a meaningful way.

## Who Are C/S/R Women?

For the purposes of this study, C/S/R women are identified as:

**C** = consumers of mental health services;

**S** = survivors of physical and/or sexual violence in childhood and/or adulthood; and

**R** = recovering from substance use/abuse.

C/S/R women also reflect the ethnicity, culture and dominant language of those being served.

## Defining Violence

A gender and culturally-specific definition of violence is one that recognizes that women are disproportionately subject to multiple forms of physical and/or sexual violence. The forms of violence frequently include childhood experiences of physical, sexual and/or emotional abuse, and revictimization in adulthood.



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# Why Integrate C/S/R Women Into Systems, Services and Research?

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Integrating individuals who have received services into the fabric of service design and delivery is not new in the fields of substance abuse, homelessness, battered women's services and mental health. Previous integration efforts generated a historical record of benefits to both individuals receiving services and provider systems. In many cases, we are building on past lessons within a current, gender-specific framework. The information provided below is based on early feedback received from the local and multi-site efforts. This information suggests improved outcomes, ranging from increased sense of self-efficacy for individuals to improved organizational environments.

## Benefits for C/S/R Women

Integration provides C/S/R women an opportunity to redefine their relationships to systems/institutions of power, and to see their opinions and beliefs take shape in the services received, changing self-perceptions (and perceptions of others) from passivity, illness and disability to empowerment, individuality, health and action. Integration can be a powerful process that results in strengthening self-esteem, changing perceptions, overcoming stigma, decreasing isolation and generating new skills while affirming prior experiential expertise.

Research and anecdotal information from substance abuse and mental health fields show that women suffer the greatest amount of violence, betrayal of trust and loss in their intimate relationships. Conversely, reparation and healing are most effective for women through the re-establishment of relationships to others.

### Benefits for C/S/R Women

- Positive role models
- Promotes specific skills
- Promotes recovery and well-being
- Increases self-esteem
- Increases sense of hope
- Cultivates self-efficacy
- Decreases isolation
- Decreases stigma

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## Service System and Research Benefits

Integrating C/S/R women can positively impact the quality of service system and research design, and implementation. The chart to the right highlights some important contributions to overall system/service environments as noted in existing literature, demonstrated through pilot projects, and personal communications. As our first year comes to a close with the Women, Co-Occurring Disorders and Violence Study, multi-stakeholder team members have reflected how integration efforts provide hope, inspire optimism, and foster empowerment and recovery while strengthening the integrity of research and service system designs.

Other experts have noted that quality of services is improved as a result of the unique understanding and subsequent contribution of people with direct experience in mental health and substance abuse systems (*NASMHPD, 1989; McCabe & Unzicker, 1995; Campbell, 1997, 1993; Fisher, 1994; Deegan, 1995*). Active C/S/R involvement at the level of research and policy planning operationalizes empowerment. Creating inclusive and empowering environments improves the chances of collaboration, improves training methods, and increases the level of organizational efficacy. Other benefits range from improved quality assurance to generating gender-specific and culturally-sensitive service delivery, sensitized policy development and informed quality assurance and oversight.

### Service/System Benefits

- Improves quality of services and systems
- Contributes systems knowledge
- Creates customer-orientation
- Positively affects policy development
- Adds diversity to environmental climates
- Reduces stigma
- Provides positive role-modeling
- Promotes increased awareness and education among co-workers
- Provides knowledge about and linkages to community and alternative resources
- Increases client engagement and retention

### Research Benefits

- Enhances research designs
- Promotes engagement of research subjects
- Broadens interpretation(s)/perspectives of research findings
- Increases research relevance

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# Barriers to Integration

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There appears to be general agreement among administrators, policymakers, researchers and clinicians regarding the *value* of recipient voice and choice. However, important differences of opinion emerge when addressing exactly *how* to successfully involve former recipients in the development and implementation of service systems and research. In an effort to understand the barriers to integration, this section examines pertinent issues identified by C/S/R women and other key players.

Barriers to Full Involvement Are Different Depending on Whom You Ask	
<i>C/S/R women cite the following barriers:</i> <ul style="list-style-type: none"><li>• Access</li><li>• Disclosure and stigma</li><li>• Finances and time</li><li>• Relevance and information</li><li>• Training</li><li>• Language</li><li>• Tokenism</li></ul>	<i>Other key players cite the following barriers:</i> <ul style="list-style-type: none"><li>• Access</li><li>• Disclosure and safety</li><li>• Finances and time</li><li>• Relevance and competence</li><li>• Training</li><li>• Boundaries</li><li>• Fear of anger</li></ul>

## Access

**C/S/R Women:** Access is defined in relationship to all other issues described by former service recipients. Practical concerns are largely financial, including reimbursement for childcare, transportation, food costs and project time associated with involvement. General barriers to important meetings, employment and training events have been explored in research pertaining to sustaining involvement of people with mental health and substance abuse concerns (*Rapp, et al., 1993; McCabe & Unzicker, 1995; VanTosh, et al., 1993; Prescott, 1998*). However, little attention has been given to the interactive effects of gender, institutional racism, and poverty in the lives of women with substance abuse and psychiatric diagnoses who

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also have histories of violence. More documentation is needed regarding the gender– and culturally–specific effects of isolation, coupled with a greater understanding of survival strategies C/S/R women have developed to combat barriers to employment and gain sustained access.

**Other Key Players:** Frequently, providers of mental health and substance abuse treatment are unsure how to generate the involvement of women and lack the awareness of how to best support and encourage active and meaningful participation. Mental health and substance abuse personnel may have limited interaction with individuals receiving services and are frequently trained to listen to them through the filters of diagnostics and deficit–orientation. Internalization of professional training can prevent viewing women as resourceful and strong once they have appeared so vulnerable. Shifting the focus from a deficit–orientation to strength–based orientation is important if collaboration among key stakeholders and C/S/R women is to be achieved and sustained.

### **Disclosure, Safety and Stigma**

**C/S/R Women:** The topic of disclosure raises strong emotional responses from both C/S/R women and other key stakeholders working in the fields of substance abuse and mental health. The topic is worthy of more exploration than allowed here. While C/S/Rs indicate that speaking about their experiences is important to recovery and healing, the stigma and related tendency to pathologize what is being said strongly discourage disclosure. Integration efforts must consider how to create safe organizational environments that foster hope, healing, empowerment and respectful collaboration in which everyone feels comfortable contributing their expertise. Fisher (1994) and others have noted that disclosure is predicated on perceptions of safety associated with being believed, acknowledged and validated. C/S/R women tend to have a strong desire to create connection with others and meaningfully contribute to the dialogue, particularly if sharing has a mission orientation and the potential to improve systems and services delivery for others. Their stories can offer tremendous insight into the complex nature of healing and system barriers, as well as amplify a vision for the course of recovery.

**Other Key Players:** Questions have been raised as to how best to support disclosure while protecting the right to choose when, where, how, and why women talk about their experiences. Key players in mental health, substance abuse, primary health, advocacy and child welfare systems are aware of the compounded losses suffered by women who have been repeatedly violated. Violation is more likely once a woman is no longer the central director of her life. For C/S/R women, loss of control in one area frequently leads to

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losses in another, creating a compounded and cumulative effect over time. This phenomenon is exemplified in the lack of adequate protections of private medical information and records, which frequently lead to loss of children in court-related custody battles (*Stefan, 1998*). The development of management information systems (MIS) has led to mandated inquiry exemplified by registration and enrollment systems (RES) that do not adequately protect women at risk. The increased lack of control over information has been known to impact the ability to obtain health insurance, damage future employment opportunities and jeopardize housing and physical safety (*Prescott, 1998*). Therefore, when C/S/Rs disclose their experiences, clinicians, policymakers and administrators must juggle their understanding of potential loss with protecting a woman's desire to be part of the dialogue.

### **Relevance and Information**

**C/S/R Women:** C/S/R women cite their lack of familiarity with the project and people involved, receiving late and/or last-minute information, and a lack of access to technology as frequent obstacles to participation. In order for integration to occur, C/S/Rs must be approached with the same priority and seriousness as any other key stakeholder with regard to project information dissemination and ongoing communication. Integration efforts are most effective when all team members — including C/S/R women — understand project goals, organizational communication practices, and how they can contribute in a meaningful way. All team member needs must be considered when arranging the best times and places to meet, and flexibility to work around scheduling needs is required.

### **Competence and Relevance**

**Other Key Players:** Frequently, there is an unspoken concern about the competence of individuals to become true partners in the collaborative process. These concerns usually arise out of a context within which clients or former recipients of services have been viewed at a time when they appeared particularly vulnerable. In addition, professional training is imbued with values and language that reflect pathology and deficit-orientation. Certain C/S/R behaviors (such as anger, inconsistent attendance, etc.) are mistakenly viewed as confirmations of pathology and vulnerability, rather than common reactions to contextual factors. Key organizational personnel may become discouraged when C/S/R women don't attend important gatherings to which they have been invited, making it less likely that the same efforts toward inclusion will be extended in the future. Former recipients may become discouraged and angry when invitations are

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extended in a way that makes actual attendance impossible (at the last minute, or without regard to transportation or scheduling needs), thereby inadvertently decreasing the chances of future participation.

## **Finances and Time**

**C/S/R Women:** Many women struggle with severe financial limitations, inadequate housing, limited community support, isolation (particularly in rural environments), and primary health care issues. Poverty is further compounded in families where women are primarily responsible for costs associated with raising children and caring for extended family members. C/S/R women relate an inherent conflict between being asked to volunteer their time to project-related endeavors and maintaining other financial or job-related responsibilities required to sustain themselves and their families.

In addition, C/S/R women frequently report differential compensation for their participation compared to other consultant salaries. This discourages teamwork and undermines a sense of being valued. C/S/R women who care for children are faced with other financial dilemmas if they receive public assistance through SSI/SSDI, medical coverage, food benefits and housing assistance. These financial concerns need to be taken into consideration when hiring and recruiting women for permanent staffing positions. If salaries are too low or do not provide benefits, C/S/R women may be discouraged from filling the positions because the resulting loss of public assistance is simply not worth the financial trade-off.

**Other Key Players:** Financial concerns are often related to time for mental health and substance abuse administrators, clinical personnel, researchers and other key project staff. Integrating C/S/R women requires increasing budgets in a number of areas detailed more thoroughly later in this manual. While some costs will certainly increase, particularly in the early stages of the collaborative process, other expenses will decrease over time as trust, clarity of roles, and involvement become operationalized.

Involving C/S/Rs in any significant way can slow the process or change the customary pace of task-orientation. This is true whenever a team adds new members, and is particularly true with any membership diversity. Slowing down can be arduous in environments that reflect the values of fast-paced communication and production. However, the process of making information accessible may require adjusting some traditional business practices. Computers, scanners, copiers, electronic and voice mail, Internet access, pagers, fax machines and cell phones are devices that now separate “professional” from those who are poor, in treatment and/or live in isolated/rural areas.

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## Language

**C/S/R Women:** Language and labels convey assumptions about women receiving services and the context of their lives. The long-term, devastating effects of labeling are eloquently described by many people who have received services in mental health, substance abuse and developmental disability communities. C/S/R women, in particular, have suffered from the compounded effect of being subject to interpersonal violence. Subsequently, they must overcome the internalization of shame, humiliation and loss of self-esteem generated by perpetrators who frequently lace threats of violence with toxic remarks. The labels assigned to women can be potent and stimulating reminders of being told they are “bad,” “manipulative,” “not credible,” “wrong” and sometimes not even “human.” Some women have cautioned that the new acronym, “C/S/R,” is a painful reminder of being referred to as “CMI” (Chronically Mentally Ill), “SMI” (Seriously Mentally Ill) and “SPMI” (Seriously and Persistently Mentally Ill). While it is a struggle to overcome the limits of prevailing deficit-based language and generate strength-based and people-first ways of speaking, making the effort creates a climate of respect and humanization.

## Training

**C/S/R Women:** Lack of training in research language/terminology presents a barrier to C/S/R women hitting the ground running in a new project or work setting. As with any new employee or team member from outside the industry, it is important to provide training that brings new team members into the setting, culture and language.

**Other Key Players:** Training is needed for both themselves and C/S/Rs. Key players reflect that they need to better understand the process of keeping C/S/R women involved and sustained in systems and services (including many of the topics outlined in this manual). Key stakeholders also understand the need for C/S/R training to ensure successful integration into new teams and organizations.

## Boundaries

**Other Key Players:** Traditional systems place value on professional and personal distance, and setting “appropriate boundaries” between themselves and those receiving services. This presents difficult dilemmas when C/S/R women are employed in the same setting where they received treatment. Negotiating



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new relationships takes time and can be uncomfortable for C/S/Rs and administrators, clinicians and staff. Each is used to perceiving the other through the lens of their training and experience. C/S/Rs are challenged to see themselves in a new way and develop relationships based on new power dynamics. Other key players face the challenge of relating to individuals receiving services as potential colleagues.

## **Fear of Anger**

**Other Key Players:** Experts who interact with C/S/R women are trained to interpret anger, frustration, sadness and other emotional responses through the lens of assigned diagnoses. In addition, key stakeholders can misunderstand the level of anger exhibited by C/S/R women. Women with psychiatric and substance abuse diagnoses and histories of violence have generally experienced enormous neglect and betrayal by people in trusted relationships. When key stakeholders make efforts to include former recipients of services, develop relationships, build trust and articulate a vision that supports their participation, they run the risk of becoming the recipients of enormous anger if they do not follow through. The depth of anger, hurt and distancing can be the compounded effect of betrayal over time.

## **Tokenism**

**C/S/R Women:** C/S/R women are diverse in experience, language, ethnicity, culture, sexual orientation, economic class, physical ability, education, skills, and stages of healing. While hiring one or two C/S/R women is a good beginning, ongoing efforts will be necessary to reflect the individual needs, wants, dreams, aspirations and personalities across many consumer groups. It is tempting in the interest of time and cost-savings to ask one or two C/S/Rs to reflect the interests of a very diverse population throughout mental health, substance abuse, trauma, and domestic violence. Clearly, that is unfair to the women being involved, and to the system that assumes it is getting more diversity and breadth of experience than any one or two people could possibly provide.

This section focused on the barriers to integration for C/S/R women into systems and services, as perceived by both C/S/R women and other key stakeholders. The next section will address strategies for integration, providing the reader with resources to address the barriers outlined in this section.

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# **Strategies and Recommended Action Steps for Integrating C/S/R Women**

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A number of demonstration projects have been designed during the last 10 years to test the efficacy of involving former recipients of substance abuse and mental health services in research and evaluation design and implementation, service development and delivery, monitoring and evaluation. However, these projects have not focused on gender-specific approaches to integrating C/S/R women.

Therefore, the following section provides an outline of suggested strategies and recommended action steps for multiple stakeholders concerned with enhancing C/S/R integration efforts. Each strategy is highlighted and followed by a number of suggestions based on new knowledge provided by the study's multiple sites and Coordinating Center during the last year. Two checklists (see pages and ) allow readers to assess their organizations for improvement opportunities to increase integration. The third checklist, "Steps Toward Empowerment in Two Parts," provides C/S/R women with questions to help ensure their needs are clear in the process of integration. We hope the strategies and approaches described will assist others attempting to engage in similar endeavors and provide a greater understanding of the opportunities and challenges that are ahead.

## **Creating an Accessible Organizational Environment for Integration**

The chances for successful sustained C/S/R involvement are greatly enhanced in atmospheres that foster flexibility and encourage and provide leadership by adapting the environment to accommodate the articulated needs and strengths of C/S/R women. C/S/R women state that successful involvement is most sustainable in climates that operationalize some of the values and characteristics listed in the chart on page 14. Organizational settings exhibiting these attributes are described as accessible, safe, supportive places in which women have opportunities to meaningfully contribute and thrive. The following information provides a template for organizations and projects seeking to proactively assess their current climate while preparing for major changes.

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## What is an Accessible Environment?

- Safe (as defined by the women)
- Flexible in policies and practices
- Supports sustainable networks of peers and allies
- Commits resources to sustainable job opportunities
- Creates equal opportunities to work, learn and grow
- Uses people-first, strength-based language
- Supports the significant representation of women for whom services are intended
- Open to feedback
- Creates accountability on all levels
- Fosters building relationships with peers
- Eliminates discrimination
- Provides ongoing oversight and evaluation
- Is culturally diverse
- Accommodating for all women, including those with physical disabilities
- Eliminates pathologizing language, clinical, research and federal shorthand
- Provides information and materials in representative languages

## Plan Proactively for Organizational Changes

Some sites have noted that preparing for large changes requires preliminary organizational preparation. Performing an informal environmental scan to ascertain the relative strengths and needs of agencies involved can provide important information about potential areas of conflict and the relative degree of “buy-in.” Some recommended steps to achieve this include:

- **Meet with multiple stakeholders early.** Meeting with community and agency stakeholders in a proactive way can generate buy-in for integration efforts and other organizational changes prior to hiring and contracting with C/S/R women. Open dialogue helps with early identification of potential conflict areas and provides a forum for addressing questions and concerns. Similar proactive meetings between agency stakeholders and C/S/R women have been useful in other research demonstration projects (*Campbell, 1993*). Because of fundamental differences between former recipients of services and professionals in identification of barriers (refer to previous section), use of language, values and perceptions of needs, it’s especially important for women to be integrated into the project planning early in the process.
- **Assess the environment.** Some examples of environmental assessments include the administration of values clarification measurements and asking former recipients of services who work in the agency to assess the level of organizational accommodation. Another way to assess the environment has been suggested in preliminary discussions with various evaluation teams. It has been hypothesized that the degree

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to which former recipients of services who currently work in agencies feel comfortable identifying their experiences within the organization may reflect on the relative “safety” of the environmental conditions (the degree to which those environments are open to inclusion). This information may be useful as projects attempt to pursue integration efforts in the future.

### **Concretize the Values of Empowerment and Involvement Through Strategic Planning**

Strategic plans optimally include definitions of terms and quantifiable measures for involvement that can be used to assess progress incrementally and longitudinally. Clarifying definitions helps guide the development and implementation of standards, which concretizes the organizational mission and vision with reference to inclusion, involvement and integration of C/S/R women. The strategic plan can also be used to develop additional sources of funding and gain support from other key stakeholders. Examples of items to consider when developing a plan are listed below.

- **Who:** Who is being targeted for increased involvement? Whose voice needs amplification in the collaborative processes?
- **What:** What does “representation” mean? Are the people being targeted reflective of the cultural, ethnic and linguistic diversity of those receiving services? Do they include people from other minority groups such as individuals with physical disabilities, lesbian and gay families?
- **Where and How:** How are “significant” and “involvement” defined? On what levels? In what areas? What percentage defines a numerical baseline and gold standard? Some agencies have recommended a target figure of 50 percent (*McCabe & Unzicker, 1995*) while others have recommended at least 33 percent.

### **Review and Adapt Policies that Present Barriers for Hiring C/S/R Women**

- **Organizational flexibility:** Willingness to review and adapt policies that present barriers to women hired as employees and involved as contractors and volunteers. In addition to concretizing values through strategic planning, other positive adaptations in organizational policies that could support successful employ-

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ment outcomes include those that focus attention in the areas of benefits, contracting and hiring, and budgeting. Some items to consider:

- **Adapt benefits that restrict leave of absence and medical absence:** There are a number of contextual factors in the lives of C/S/R women and their children that may challenge organizations with strict benefits policies. Therefore, proactive review and adaptation of benefits can be particularly helpful in anticipating problems before they arise. Some circumstances to consider are: substance use relapse while working; re-engagement in psychiatric inpatient and/or substance abuse treatment and/or temporary dislocation due to violence or poverty; fluctuating states of physical wellness and demise due to HIV; and adjustment to medications.
- **Revisit the organizational bereavement benefits:** The way the term “family” or “immediate family” is defined is important in policies governing time off to attend funerals, memorial services and other activities associated with loss. Definitions of family are dependent on sexual orientation, culture and the circumstances that impact C/S/R women, such as HIV status, alcohol/drug use, hospitalizations, incarceration, and violence. C/S/R women are at much higher risk for repeated victimization and witnessing the death of people in their support network. Many of these women have lost “traditional” family members through death, rejection and/or distance. Therefore, supportive networks have often replaced “traditional” family and may be defined as extended family members and close friends.
- **Create provisions in contracts and hiring policies that substitute academic degrees for “lived experience” and other relevant expertise:** In order to create opportunities and underscore the value of expertise generated through life experiences, some agencies have successfully substituted experiential criteria for academic degrees when developing contracts and hiring former recipients of services.
- **Develop flexible work provisions in hiring and scheduling:** Organizations increasingly recognize the need for and benefit of flexible scheduling. Individuals who have mental health and substance abuse disorders and histories of violence may find standard office environments extremely distracting, stressful and re-stimulating. While some C/S/R women may thrive in these environments, others will respond in ways that make them appear “unpredictable,” “tense” and “overwhelmed.” Flexible scheduling can lead to a win-win situation for employer and employee. Organizations frequently find that flexible scheduling results in greater work production and cost savings in terms of space and individual satisfaction.

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- **Allocate line items in agency budgets for C/S/R development and recruitment, training, administrative support, extra knowledge product development, and dissemination costs:** In the early stages of C/S/R development and recruitment, there can be a number of unanticipated expenses. Some of the line item increases pertain to training, traveling and phone expenses (conference calls among C/S/Rs). Telephone costs can be particularly high if women live in rural, isolated areas and the phone is their primary form of communication. Information may need to be adapted for individuals who have hearing or sight impairments, and interpreters may be required to translate existing material and/or facilitate at working sessions that include women from other cultures. Travel and meetings are important to consider since many women will want to meet each other face-to-face rather than through telecommunication. Other expenses relate to consultant fees if mentors are hired; extra meetings for C/S/R women to gather, plan and train; and preparing cash advances so C/S/R women can pay for hotel, food, taxi and other travel costs when meetings are held out of the area.

### **Provide Comprehensive Orientation, Leadership, Skills Development and Cross-Training**

Consistent and relevant briefing has frequently been used to build confidence, decrease isolation and increase full participation in collaborative endeavors concerning research, service system design and delivery. Consider the following techniques when briefing:

- **Use train-the-trainer model** in orientation, leadership, skills development and cross-training in order to continually expand available pools of trained individuals.
  - **Provide two-part orientation training**, one with only C/S/R women and another with other key staff and C/S/R women together.
  - **Follow orientation** with leadership training, advocacy and skills development training.
  - **Co-facilitate training sessions** with C/S/R women and other staff to model partnerships.
  - **Review topics such as:**
    - Project and agency missions; goals; structure; research and project language; personnel; roles; opportunities for participation, involvement and employment;
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- Advocacy; human rights; assertiveness; boundary clarification; diversity; becoming familiar with and accessing resources and information, including communications technology; conflict resolution and stress management; network development;
  - Co-facilitation skills; becoming an ally with other key staff members (for C/S/R women); how to become an ally with C/S/R women (for other key staff members).

### **Approach C/S/R Women as Resource Experts**

A common misunderstanding is that advocate and/or adjunct organizations who “speak for C/S/Rs” are endorsed by women receiving services. There is often a marked difference in values, preferred approaches, definitions, and priorities between C/S/R women who have experienced service delivery and those who consider themselves “secondary consumers.” Agency, research and other key stakeholders are encouraged to speak directly to C/S/R women regarding referrals to groups they find helpful. Encouraging C/S/R women to find their “own voices” and to speak for themselves signals an affirmation of a commitment to them, and models respectful engagement. Consider the following suggestions when approaching C/S/R women:

- **Ask C/S/R women about peer-operated groups in the area and/or state:** Develop a relationship with those groups they recommend. Call and ask for information, and attend trainings, meetings or activities at their sites/offices.
- **Become familiar with C/S/R-identified/authored literature and resources:** (Some references are listed in the back of this manual).
- **Other steps for creating buy-in include:**
  - Asking C/S/R women what interests them about the project. Start involvement at the levels they identify.
  - Ask C/S/R women what they enjoy doing, what motivates them, what skills they excel at and what skills they hope to learn through this job.
  - Have a range of opportunities available for involvement so that women who are shy or already overly committed can still participate in ways that are valuable and relevant.

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## Create and Disseminate Clear Communications and Information

It is difficult to overemphasize the importance of providing clear, timely and relevant information in a language women understand when attempting to build trust and a strong, sustainable presence of C/S/R women in any project endeavor. Concerted and consistent efforts must be directed toward keeping women “in the loop” about events, meeting dates and phone calls at local, state and federal levels. Creating a formal and reliable information loop will maximize control, choice, buy-in and partnership. Communication styles vary by culture, and access to communication technology varies by income levels. Consider the following communication tips:

- **Utilize the kind of communication each C/S/R woman prefers**, whether it be written, verbal, e-mail, or other.
- **Provide information in a way that uses “people-first” language** (avoids jargon).
- **Monitor the use of deficit-based language.**

## Tailor the Meeting Environment

Tailoring the environment has to do with accommodating individuals who might wish to become involved but are least likely to engage and actively participate. Some specific recommendations for these accommodations are listed below:

- **Plan enough time for women to speak at meetings.**
- **Reflect what C/S/R women say.** While reflecting back what someone says is a useful, active listening tool for anyone, C/S/R women may require additional sensitivity to the kinds of efforts it takes to participate equally. Many C/S/R women have worked hard to keep their particular vulnerabilities hidden, so it may be useful to adapt the environment to accommodate the most potentially “shy” member. The reasons why women may be afraid to speak up, wait until the last minute, or take a longer time than others to articulate what they want to say pertains to a variety of factors. Some examples of reasons provided by C/S/R women are: hearing voices; withdrawal from medication, alcohol, drugs; taking medications that alter thought processes, produce side effects in speech, appetite, coordination, and hydration; low self-esteem often stemming from abuse (they are convinced they “don’t make sense,” “don’t have anything



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useful to contribute,” etc.); post-traumatic stress responses to enclosed and crowded environments; fear generated from being dominated by those in authority.

**Hold meetings in the communities women live or in a neutral place.** Some gatherings and work meetings have been cancelled due to lack of attendance. While there are a number of possible explanations, there are a few worth explicating further. Meetings that are scheduled in institutional settings such as inpatient psychiatric units, jails, or therapeutic communities that are highly restricted can be difficult for people who formerly received services and may not want to return. Scheduling work groups, etc., in offices that are programmatically associated and/or community treatment centers may provide access for C/S/R women in treatment, but it may not provide the continuity a project desires. Therefore, meeting women in the communities they live, in addition to program-related settings, has been recommended.

**Adapt physical space in ways that are accommodating.** There is immense variability in how C/S/R women respond to the physical design of a room. However, there are a few common themes worth highlighting. If possible, avoid blocking entries and exits, overcrowding with tables and chairs (so people are prevented from passing between them), sitting in circles (although some women prefer this), and sitting or standing behind women.

### **Sponsor Activities that are Fun, Informal and Interactive**

Team members are more apt to contact or assist someone they have met face-to-face. Informal, organization-sponsored activities such as retreats and gatherings can be helpful in building trust. Activities don't need to be expensive or lengthy, but providing snacks and a meeting venue after working-hours can help “break the ice” and facilitate a sense of teamwork. Also, approach C/S/R women and ask what they like to do to relax and make plans involving those activities. Sites have engaged in the following activities with C/S/R women: attending outdoor and cultural events; having coffee/tea; going for walks; playing sports; having/providing lunch; attending museums; going on bus tours; drumming circles; and others.

### **Hire and Compensate C/S/R Women at Competitive Wages**

Providing a range of opportunities for C/S/R women to become involved in project activities is an important strategy in supporting diversity and sustaining integration efforts over time. One of the top recommendations made by key stakeholders in the study pertains to employing C/S/R women within formal agency structures

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and paying them competitive wages. When C/S/R women are not filling “official” (usually structured) positions within agency hierarchies or paid for their time in a substantial way, they are unable to adequately participate in necessary conference calls, committee work and ongoing meetings. In addition to being the preferred method of communication and knowledge transfer, conference calls, committee work and subcommittee meetings are vital to team–building and initiation of cross–collaborative partnerships. Design meaningful positions that compensate C/S/R women enough so they don’t have to compete with multiple priorities to become involved and integrated into essential project endeavors.

### Create a Range of Opportunities for C/S/R Women

Another key strategy to creating accessible environments where women feel valued, empowered and find hope involves providing an array of opportunities for C/S/R women to engage in the project. Roles for C/S/R women range from intermittent participation in less formal forums to more formal and structured positions that are part of the permanent staffing structure. The chart to the right provides examples of formal and informal positions created by and for C/S/R women within the last year as the sites and Coordinating Center worked to meaningfully operationalize the strong values articulated in the GFA.

### Increase the Number of Role Models and Mentors

Enlarging the number of role models (C/S/R women who share similar experiences) creates diversity and increases opportunities for shared learning, collaboration and retention in project activities. Further, role models and mentors have been used to facilitate ongoing, in–house education in addition to confronting common myths and stereotypes about C/S/R women. Expanding the number of women with these experiences in

Examples of Positional Stratification	
<b>Most Formal</b> C/S/R Integration Coordinator Principal Researcher Research Assistants Case Manager/Trauma Specialist Director of Orientation and Leadership Training Community Development and Outreach Coordinator Co–Evaluator Knowledge Development Media Specialists Project Historian	full– and part–time paid positions
<b>Less Formal</b> Team Members: Clinical Review Research Review Consumer Assessment Knowledge Development Technical Assistance Research Interns Training Co–Facilitators	part–time and consulting positions
<b>Least Formal</b> Focus Group Participants Advisory Board Members Leadership Council Members	generally

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multiple forums decreases the relative burden on one or two women officially hired or involved. Consider the following:

- **Create a “gold standard”** to work toward when attempting to enhance representation.
- **Avoid having only one person representing C/S/R women. Strive for at least two at any given time.** Otherwise, C/S/R women can be at risk for “burn-out” as the dangers of multi-tasking increase over time.

### **Create Innovative and Socially-Valued Roles**

In whatever capacity C/S/R women are involved, they articulate the need for socially valued roles that have clearly defined goals, objectives and tasks. Innovative roles and associated tasks have evolved in the areas of executive management; training and education; research and evaluation; community education and development; service delivery and outreach; knowledge development; monitoring and oversight; and volunteer activities. There is a lack of standardized role definitions and associated tasks across the sites at this early stage of project development. Therefore, some of the titles for C/S/R positions vary from site to site and some of the responsibilities assigned to women in these roles overlap. The “Chart of Position Titles and Tasks” is an attempt to provide a template for future standardization of action steps pertaining to the development of broad-based opportunities and innovative roles for C/S/R women.

The cells shaded with dark gray represent primary responsibilities; cells shaded with light gray represent partial responsibilities and/or important teamwork efforts.

Chart of Position Titles and Tasks	Most Formal ← → Least Formal											
	C/S/R Integration Coordinator	Director of Orientation and Leadership Training	Principal Researcher	Research Assistants and Interns	Community Education and Development Coordinator	Project Historian	Knowledge Development; Media Specialist	Case Manager/Trauma Specialists	Training Co-Facilitators	Consumer Assessment Team Mem.	Peer Advocates/Specialists	Advisory Board Members
<b>Executive Management</b>												
• Review budget												
• Assist in developing strategic plan that includes standards for enhancing C/S/R involvement												
• Supervise/coordinate local C/S/R team members												
• Gather information on site-specific and national (cross-site) integration efforts												
• Develop quarterly reports on progress toward integration for internal use and presentation												
• Meet regularly with knowledge development team to discuss lessons learned from collected data and refine information for dissemination												
• Act as a liaison to national (cross-site) and local (site-specific) executive committees regarding increased C/S/R integration and progress												
• Work with research team to develop indicators for measuring C/S/R integration at site-specific and cross-site levels												
• Devise a communication system with C/S/Rs												
• Provide technical assistance on C/S/R integration												
• Participate in national and local policy review												
• Attend national cross-site meetings												
• Participate in cross-site subcommittee activities												
• Participate in local and national conference calls												
• Coordinate C/S/R participation in site visits												
• Meet regularly with local C/S/Rs to update them on national activities and obtain feedback												
• Develop draft Request for Proposals (RFPs) for the procurement of services												

■ = primary responsibility      ■ = partial responsibility and/or important teamwork effort

Chart of Position Titles and Tasks	Most Formal ←————→ Least Formal											
	C/S/R Integration Coordinator	Director of Orientation and Leadership Training	Principal Researcher	Research Assistants and Interns	Community Education and Development Coordinator	Project Historian	Knowledge Development; Media Specialist	Case Manager/Trauma Specialists	Training Co-Facilitators	Consumer Assessment Team Mem.	Peer Advocates/Specialists	Advisory Board Members
Training and Education												
A. C/S/R Orientation												
• Write orientation package												
• Co-facilitate delivery (train-the-trainer model)												
1) Review project history, structure and language												
2) Define goals, roles and opportunities												
3) Train C/S/R women to deliver orientation												
B. Leadership, Advocacy and Skills Development												
• Write training packages												
• Co-facilitate delivery (train-the-trainer model)												
1) Review leadership and advocacy skills												
2) Familiarize C/S/R women with technology												
3) Refine co-facilitation skills												
4) Foster network development												
C. Cross-Training												
• Write training packages												
• Co-facilitate delivery (train-the-trainer model)												
1) Orient new project staff, key community stakeholders, consultants and C/S/R women												
2) Deliver training on becoming allies with C/S/Rs												
3) Topical cross-training on project subject areas												



 = primary responsibility     
  = partial responsibility and/or important teamwork effort

Chart of Position Titles and Tasks	<div>Most Formal ←————→ Least Formal</div>											
	C/S/R Integration Coordinator	Director of Orientation and Leadership Training	Principal Researcher	Research Assistants and Interns	Community Education and Development Coordinator	Project Historian	Knowledge Development; Media Specialist	Case Manager/Trauma Specialists	Training Co-Facilitators	Consumer Assessment Team Mem.	Peer Advocates/Specialists	Advisory Board Members
Research and Evaluation												
• Conduct qualitative interviews												
• Design protocols and research instruments												
• Review research material, collect and clean data												
• Attend local research design meetings												
• Meet with local research team to share info.												
• Participate in cross-site research meetings and calls												
• Develop and review service models and approaches												
• Review outcome measurements												
• Collect and thematically code qualitative data provided by project historian												
• Train C/S/R research interns in qualitative research design and field testing (train-the-trainer)												
• Conduct/co-facilitate focus groups												
Community Education and Development												
• Identify community groups for education and training, project publicity												
• Schedule meetings with stakeholder groups such as church groups, shelters, and advocacy organizations												
• Identify consultants in agency and community settings for cross-training												





 = primary responsibility     
  = partial responsibility and/or important teamwork effort

Chart of Position Titles and Tasks	Most Formal ←————→ Least Formal											
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Service Delivery and Outreach												
• Identify community resources and alternative peer-operated services												
• Facilitate connections with services and support												
• Create and direct support groups for and with C/S/R women in multiple settings (jails, in-patient, therapeutic communities, battered women’s shelters) on gender-specific topics												
• Meet with C/S/Rs in the community to develop trust, rapport, conduct outreach, provide information												
Knowledge Development												
• Coordinate newsletter, video and other multi-media productions to generate interest in the project and advertise current learning												
• Coordinate publicity and dissemination by writing fliers, newspaper and radio advertisements												
• Work with research, training and technical assistance teams to develop products												
• Work with C/S/Rs to document and archive the lives of the women served and integration efforts through video, audio tape, etc.												
• Work with community development and outreach team to develop speaker bureaus of C/S/R women who are engaged in the project												
• Educate local and state media about advantages of C/S/R-friendly mental health, substance abuse and trauma service systems												
• Develop linkages with newspapers, television, radio personnel to cover innovations being developed												

= primary responsibility
  = partial responsibility and/or important teamwork effort

Chart of Position Titles and Tasks	Most Formal ←————→ Least Formal											
	C/S/R Integration Coordinator	Director of Orientation and Leadership Training	Principal Researcher	Research Assistants and Interns	Community Education and Development Coordinator	Project Historian	Knowledge Development; Media Specialist	Case Manager/Trauma Specialists	Training Co-Facilitators	Consumer Assessment Team Mem.	Peer Advocates/Specialists	Advisory Board Members
	Monitoring and Oversight											
	• Measure performance and ongoing evaluation											
	• Engage in quality assurance activities											
	• Review standards and policies pertaining to some of the following: service delivery, utilization reviews, risk management protocols, human subject research											
	• Review policies and practices pertaining to: informed consent, medical record privacy, satisfaction survey responses, restrictive procedures/interventions known to negatively impact C/S/R women and their children											

 = primary responsibility     
  = partial responsibility and/or important teamwork effort

Many people made reference to the importance of the activities listed below. However, they were not assigned to any particular job title above. These include

- Participation in focus groups
- Providing transportation for C/S/Rs
- Participation in leadership councils
- Participation in support and empowerment groups
- Provide input and feedback regarding: level of satisfaction regarding service delivery, defining barriers to access
- Donating life stories for documentation purposes



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## Provide Supervision

Adaptive environments frequently have a principal person who takes responsibility as a primary contact and mentor. Guidance focuses on teaching advocacy skills and supporting women in their changing roles. Clarity of expectation/responsibilities and performance evaluation are often provided with particular attention given to the meaning and complexities of managing multiple roles. Encouragement and reinforcement of accomplishments can prove integral in sustaining interest and involvement. In formal environments, these positions are often designated for someone in a supervisory position who acts as a liaison to the executive management team, creating a single point of accountability within agencies and/or across sites. Supervisors also can serve as role models and mentors most effectively when they have experienced the transition from former “clients” to “providers” working in the field. Fisher (1994) notes that when this arrangement is not available, supervision is best performed by women who share the same values. Below are suggested guidelines for dealing with supervision.

- **Provide the option of individual C/S/R mentors for new participants:** These women can act as “sponsors” and/or principal contact people for new participants.
- **Hire a C/S/R Integration Coordinator:** In the midst of attending to multiple priorities, C/S/R coordinators can help assure local, regional and national project personnel that integration efforts are being streamlined and actively represented at multiple levels. She also acts as a powerful role model for other potential employees, staff and funding agents. Her position can be pivotal in enhancing system efforts to integrate women in meaningful ways by creating a single point of accountability for these endeavors within an agency. While C/S/R coordinator positions have been defined in various ways, some critical responsibilities are briefly outlined in the previous chart.

## Create Clear Roles and Responsibilities

As mentioned earlier, hiring and contracting with former recipients of services is not new to the fields of substance abuse, domestic violence and more recently, mental health. However, the lack of established standards for specifically hiring *women* who have received services for mental health *and* substance abuse concerns, *and* who also have histories of violence speaks to the depth of invisibility of this particular group. In the genesis of any new project and organizational change, there is frequently conflict and confusion about roles and expectations. However, this conflict can have specific performance ramifications for C/S/R women who have

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been negatively impacted by the unpredictable behavior (abuse and violence) of others, and by erratic social and economic conditions. Many C/S/R women thrive best in environments that provide clear expectations, roles and responsibilities. Organizational attention to this area increases the chance of successful individual achievement, bolstering self-esteem and combating the negative perception of C/S/R women as highly “vulnerable” and stereotypically “unstable.” Consider the following strategies:

- **Develop roles and tasks that are as clear and consistent as possible.** Predictable expectations are important to maximize chances of success and a sense of safety.
- **Reassess tasks together frequently.** It helps to generate ideas and descriptions about jobs, roles, and titles from a variety of sources ahead of time. Proactively approach a diverse group of women, from individual C/S/R women who are employed at the site or other agencies to C/S/R groups who are not currently employed.

### **Measure and Monitor Your Progress**

There are a number of ways to measure and monitor the level of C/S/R integration, active representation and degree of involvement. Some recommendations are listed below.

- **Measuring:**
  - Set numerical standards that are achievable over time;
  - Create a cross-collaborative forum (work group, subcommittee, etc.) that focuses on the tasks associated with measuring and monitoring C/S/R integration efforts and makes recommendations to the executive team;
  - Develop a self-report scale with C/S/R women that rates some of the following:
    1. degree to which women’s strengths are being utilized and encouraged;
    2. increase and decrease of barriers to integration encounters;
    3. degree to which allies and community linkages are developed and maintained;
    4. increase and decrease of a sense of well-being, autonomy and efficacy; and
    5. extent, ease, and repercussions of disclosure.

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**Monitoring:**

- Develop a timeline and process for implementing ongoing evaluation;
- Develop a position(s) and/or team(s) that acts as the point of accountability for monitoring integration efforts. It is suggested that this person(s) be a C/S/R woman who is a liaison and permanent member of the quality assurance, evaluation, and executive management teams.

## **Document Everything**

Information currently being generated on how to effectively integrate C/S/R women into all phases and all levels of project design and implementation can lead the way for new projects concerned with C/S/R integration in the future. Therefore, documenting the process from the beginning provides invaluable insight into the strategies employed, barriers encountered, lessons learned, and new approaches developed to achieve the best possible outcome. Consider the following documentation strategies:

- **Document through multi-media:** Using multi-media helps generate ongoing, qualitative archives of important developmental shifts in project goals, strategies, service/system approaches, research design and integration efforts.
  - **Designate roles for C/S/R women to become project historians:** Using multi-media to capture the process as it unfolds can be an exciting way to engage women at various stages of participation in team efforts. Having designated roles for C/S/R women to interview others about the opportunities, barriers and recommendations from their perspectives can be fun and powerful for later presentation. Video recordings, audio cassette tape accounts, and writing can provide a rich context for quantitative outcome data as it is developed.
  - **Share information with individuals unable to attend meetings, conferences and work groups:** Having a meeting with everyone present is not always possible. In those cases, and to accommodate members who may have trouble with vision, retention and reading, audio cassette tapes have been used to provide necessary information. In addition, recordings have provided a mechanism to keep team members informed about site-specific needs and technical assistance requests.
  - **Document incremental changes, achievements and challenges:** They also provide important documentation of changes over time as the sites move toward their stated goals.
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- **Advertise integration efforts:** Documentation through multi-media provides a powerful and convincing portrait of the work being accomplished and can facilitate increased buy-in from other community stakeholder groups and funding sources.

This section has provided an overview of strategies and recommended action steps for integrating C/S/R women into systems and services, including specific job tasks and functions. The reader is encouraged to use the self-checks at the end of the document to assess organizational and individual levels of awareness and integration orientation.

## **Challenges for the Future**

There are a number of struggles articulated by the 14 sites that provide a template for future challenges as projects attempt to integrate a sustainable presence of C/S/R women into project endeavors. Some of the more pressing areas of concern are outlined below.

**Sustaining C/S/R involvement with women in early recovery.** It seems more difficult to engage women in early recovery because of the context of their lives. Women who leave residential services tend to end their participation in the project as they move out of the area.

**Increasing voice and volume.** The numbers of C/S/R women on consumer advisory boards and in management positions need to grow stronger and become more diverse. Increasing numbers of C/S/Rs willing to speak publicly about their experiences are needed as well.

**Time and outreach for relationship-building.** A great deal of outreach and relationship-building appears necessary to keep women involved.

**Dual roles.** The dual roles of C/S/Rs employed as independent contractors and continuing in aftercare leads to conflict. There is a need for more direction in developing clear roles and policies in addressing dual and boundary-spanning roles.

**Access to technology.** Ongoing poverty and geographic/rural isolation issues create special challenges in providing easy access to e-mail for C/S/R women who do not have a computer at home. There is a desire to test the efficacy of providing computers and communication technology to women on their level of empowerment.

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**Financial resources to support C/S/R growth.** How will increasing C/S/R development be supported?

**Implementation of values.** One of the largest challenges in the future will be how to give C/S/R women a voice not only in principles behind clinical interventions but the way those principles are implemented. This will involve providing input about how mental health and substance abuse professionals practice and the way resources are allocated.

## Conclusion

While there are many challenges associated with integrating C/S/R women into service system and research design and implementation, the process is often extremely rewarding. Like many complicated, multi-level tasks, it can yield significant and lasting systemic and individual changes. There are many questions regarding best practices for integrating C/S/R women currently generated from the ongoing collaborative work at local, state and national levels. In an effort to deliver a product that is user-friendly, we have deliberately kept this guide brief and, therefore, have not addressed many of these questions. However, some of the questions that project participants face as the study moves into Phase II are:

- How are the values of C/S/R integration actualized as service delivery and research is implemented at the 14 sites?
- What site-specific and multi-site impact does C/S/R integration have on the:
  - project as a whole;
  - women who will receive services;
  - instrumentation developed to measure outcomes; and
  - interpretation of findings?
- In what ways can C/S/R integration efforts be enhanced that create sustainability?
- And as the project progresses, what will be the most effective measures of the costs and benefits?

We have learned quite a bit in the last year about ourselves, our capacities, our commonalities and differences. Together we have traveled critical pathways that have led to new understanding, and opportunities for investigation and exploration. The challenge of developing good science that accurately addresses and reflects the full

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context of the lives of women who have received services can be daunting. However, it is this unique opportunity that brings over a hundred women to Washington, DC, every three months, and it is here that each has a voice that represents hundreds of others who stay behind. Perhaps the successes are best reflected in the words of a woman who attended a national steering committee meeting for the second time: “I know how to ask the questions now. I can contribute.” And it is this kind of contribution that holds potential for new partnerships in collaboration as the project moves forward into the future.

## Checklist #1: Organizational Assessment

Yes	No	Developing Strategies for Sustainability
<input type="checkbox"/>	<input type="checkbox"/>	Is there a strategy for involving C/S/Rs in key roles?
<input type="checkbox"/>	<input type="checkbox"/>	Is there a specific plan for outreach and recruiting in the community?
<input type="checkbox"/>	<input type="checkbox"/>	Does the strategy specifically target diverse groups of women?
<input type="checkbox"/>	<input type="checkbox"/>	Is there a focus on activism?
<input type="checkbox"/>	<input type="checkbox"/>	Are the project goals and activities relevant enough to sustain the interest of women involved?
<input type="checkbox"/>	<input type="checkbox"/>	Is there a plan for C/S/R training, continuing education and development?
<input type="checkbox"/>	<input type="checkbox"/>	Are there formal and informal retention strategies (employee assistance programs, etc.)?
<input type="checkbox"/>	<input type="checkbox"/>	Is flex-time offered?
<input type="checkbox"/>	<input type="checkbox"/>	Is there more than one position specifically designed for C/S/R women who publicly disclose their experiences?
<input type="checkbox"/>	<input type="checkbox"/>	Is there peer and/or collegial support for C/S/R women who publicly disclose their experiences?
<input type="checkbox"/>	<input type="checkbox"/>	Are there opportunities to openly discuss the impact of disclosure and stigma?
		<b>Increasing the Numbers</b>
<input type="checkbox"/>	<input type="checkbox"/>	Are there numerical targets for increasing C/S/R presence?
<input type="checkbox"/>	<input type="checkbox"/>	Are there incremental increases over time?
<input type="checkbox"/>	<input type="checkbox"/>	Do they include a breakout for diversity (examples: women of color, disabled women)?
		<b>Creating Valued and Meaningful Roles/Positions</b>
<input type="checkbox"/>	<input type="checkbox"/>	Are the roles defined?
<input type="checkbox"/>	<input type="checkbox"/>	Are the tasks assigned to the roles specific and measurable?
<input type="checkbox"/>	<input type="checkbox"/>	Are there ongoing, planned/scheduled communications with C/S/Rs?
<input type="checkbox"/>	<input type="checkbox"/>	Is there ongoing formal communication with individuals hired for specific tasks?
		<b>Funding/Budget and Resources</b>
<input type="checkbox"/>	<input type="checkbox"/>	Is there a separate line item for full-time C/S/R employment, training and continuing education?
<input type="checkbox"/>	<input type="checkbox"/>	Is there adequate reimbursement money allocated for childcare, travel and food expenses?
<input type="checkbox"/>	<input type="checkbox"/>	Will you offer honorariums, stipends, or consulting contracts?
<input type="checkbox"/>	<input type="checkbox"/>	Is there compensation parity between C/S/R workers and other workers in the same position or performing identical duties?
<input type="checkbox"/>	<input type="checkbox"/>	Are there budget line items included for development <b>and</b> implementation?
<input type="checkbox"/>	<input type="checkbox"/>	Has the organization asked recipients to identify other local resources to provide training and support?

## Checklist #2: Some Questions and Potential Accommodations to Consider

Questions	Accommodations
<input type="checkbox"/> Is English the C/S/R's primary language?  <input type="checkbox"/> Does anyone have a physical disability?           <input type="checkbox"/> Is the environment conducive to productivity?           <input type="checkbox"/> Is the C/S/R representative currently employed elsewhere? <input type="checkbox"/> Is the C/S/R representative currently in school? <input type="checkbox"/> Is the C/S/R representative currently in treatment?           <input type="checkbox"/> Does the C/S/R and the team have proper equipment to communicate?	<input type="checkbox"/> Does the organization need an interpreter?  <input type="checkbox"/> Do the meetings need to be held in an accessible place? <input type="checkbox"/> Are there accessible bathrooms? <input type="checkbox"/> Does the organization need to contract with someone who speaks American Sign Language? <input type="checkbox"/> Does the material need to be printed in large print? <input type="checkbox"/> Is there enough light? (meeting areas well lit?) <input type="checkbox"/> Does the person have environmental sensitivities?  <input type="checkbox"/> Is there anything (chairs, tables, equipment, debris, ice) blocking entry/exits? <input type="checkbox"/> Is entry/exit easily accessible? Is the building secure? <input type="checkbox"/> Is there water? Food? Telephone to call a cab if necessary? <input type="checkbox"/> Ask if women prefer being in a circle. Circular seating patterns are uncomfortable for many survivors. <input type="checkbox"/> Are there pads, pens and paper to take notes? <input type="checkbox"/> Are there enough breaks? (every hour or hour and a half) <input type="checkbox"/> Are nighttime meetings possible? Is parking safe and available? <input type="checkbox"/> Are walkways well-lit and clear?  <input type="checkbox"/> What are their schedule needs? <input type="checkbox"/> Is compensation available for time missed at work? In school? <input type="checkbox"/> Are meetings scheduled with enough time for input from everyone? <input type="checkbox"/> Is the C/S/R consulted about the schedule? <input type="checkbox"/> How do schedule change notifications occur?  <input type="checkbox"/> What is the primary form of organization or team communication? <input type="checkbox"/> Does the C/S/R have unrestricted access to the necessary equipment to participate, such as a speakerphone, fax machine, computer, Internet access, long-distance phone access or phone card? Transportation to meet principal players? <input type="checkbox"/> Does the C/S/R representative have the necessary training or experience to use this equipment effectively?



## Steps Toward C/S/R Empowerment (Two Parts)

Women can empower themselves by asking relevant questions about their roles and positions in the organization or project they are joining. The examples provided in Part I below can be used and/or adapted to guide C/S/R women and organizational personnel in an early dialogue about their future collaborative work. While Part I reflects an external exploration with future partners, Part II raises questions for C/S/R women to explore privately when making decisions about changing roles and becoming actively involved.

Part I		
Sample Questions		
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is there a job description that outlines my role?
		If not, what is the definition of my role?
		How will it be presented to people here and in other places?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is the position stable?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Will I have a mentor?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Are there other C/S/R women working in the organization or at the project site?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is there a performance review process?
		How often? Who reviews my performance?
		What is my hourly pay rate? How will I get paid? How often and when will I get paid?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Are there benefits that come with the position?
<input type="checkbox"/> yes	<input type="checkbox"/> no	If the position is volunteer or contracted, will I be reimbursed for costs involved in taking this position?
		Which costs (transportation, food, childcare, phone calls, mail, copying, etc.)?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is transportation provided?
<input type="checkbox"/> yes	<input type="checkbox"/> no	If not, will I be reimbursed for transportation costs?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is childcare provided?
<input type="checkbox"/> yes	<input type="checkbox"/> no	If not, will I be reimbursed for childcare costs?
		If so, where and by whom?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Will the organization deduct federal, state and FICA taxes, or am I considered an independent consultant responsible for declaring my own taxes? (Note: employers pay 7.5%, or 1/2 of an employee's FICA tax, but independent contractors pay the entire tax and are responsible for filing quarterly tax reports)

## Part II

Sample Questions		
<input type="checkbox"/> yes	<input type="checkbox"/> no	Am I excited about the position?
		Why or why not?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is my role clear? Do I feel as though I know what to do?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Are the expectations of the position realistic? Too high? Too low?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Do other people know what I do in my position?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Does this position support my goals and aspirations?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Are there training and educational opportunities that come with this position?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Are there skills I can learn that will help me in the future?
		What are they?
		What information do I need to do my job and where can I get that information?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is the person with information available to me?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Will I have another C/S/R woman to help mentor me in my position?
		How does the organization define teamwork? Do I have guidance and autonomy?
<input type="checkbox"/> yes	<input type="checkbox"/> no	If I need support on the job, is it available and confidential?
		How will I be supported if I make mistakes?
<input type="checkbox"/> yes	<input type="checkbox"/> no	If the agency provides benefits, will it cover the costs of medical care for my children, partner and/or other family members?
		What is the structure of decision-making, and how do I fit into it?
<input type="checkbox"/> yes	<input type="checkbox"/> no	Is there peer and/or collegial support to discuss potential problems that might arise as a result of disclosing my experiences?

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## Appendix II: Helpful Resources

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Several organizations have successful models for hiring and integrating C/S/Rs. For more information, contact the organizations below.

### **Advocacy — Peer Run Organizations — Training**

#### **Alaska Mental Health Consumer Web Computer Connection**

619 E. 5th Ave., Suite 212,  
Anchorage, AK 99501  
Telephone: (907) 222-2980  
Fax: (907) 222-2981  
<http://akmhweb.org/>

This is a nonprofit corporation for Alaskan mental health consumers to learn about Alaskan consumer issues and events. The up-to-date website encourages consumers to submit their material for publication on the Internet. An online support group is run weekly. Information on employment, housing, Internet, publications, and more is also provided online. Consumers run the Computer Connection, which houses computers for consumers to use (started with three and now have 10), along with various activities, such as social events, Tai Chi, Internet classes, presentations on vocational rehabilitation, and a class on grant-writing in the future. There also is a Peer Counseling Committee available, which does 24-hour crisis intervention.

#### **Advocacy Unlimited, Inc.**

300 Russell Road  
Wethersfield, CT 06109  
Telephone: (860) 667-0460  
Fax: (860) 667-2240  
<http://www.mindlink.org/>

Directed and controlled by consumers, this group advocates for initiatives that further individual rights and choices, and facilitates representation, support and education for people affected by psychiatric disabilities and/or for people who are in recovery. Also actively involved in the service delivery system, the legislative process, public education, and coalition-building.

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**CONFIDENT, Inc.**

5700 Florida Blvd., Suite 510

Baton Rouge, LA 70806

Telephone: (504) 927-7622

(800) 471-3444

Fax: (504) 927-7856

<http://www.contac.org/confident/>

CONFIDENT, Inc., is a statewide, nonprofit organization that helps empower mental health consumers in Louisiana. Consumers direct and run a drop-in center called Les Bon Amis.

**Consumer Support Services, Inc.**

<http://www.cssinc.org/home.shtml>

A nonprofit mental health corporation that operates The Springfield Center and The Riverhouse, a new drop-in center.

**The Springfield Center**

157 E. 8th St., #116

Jacksonville, FL 32206

Telephone: 904-359-2511

Fax: 904-359-2513

<http://www.cssinc.org/spgfldct.htm>

The Springfield Center is a drop-in center, developed and controlled by consumers, for consumers/survivors/ex-patients, that provides socialization, relaxation, recreation, education, and support groups. Provides supportive employment programs for consumers.

**Consumer Organization and Networking Technical Assistance Center (Contac)**

1036 Quarrier St., Suite 208-A

Charleston, WV 25301

Telephone: (888) 825-tech

(304) 346-9992

Fax: (304) 345-7303

<http://www.contac.org/>

Contac is a resource center for consumers/survivors/ex-patients and consumer-run organizations across the United States. Its website provides extensive links and information on how to contact consumer-run organizations.

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**Delaware Mental Health Consumers Coalition**

100 W. 10th St., Suite 409

Wilmington, DE 19801

Telephone: (302) 654-7455

Fax: (302) 654-7462

<http://www.idealists.org/cgi-bin/IS/detailed.pl?org!Deleware+Mental+Health+Consumers+Coalition>

Working against the use of coercion or punishment in the mental health system, this coalition of consumers/survivors and ex-patients aims to make the system more responsive to them and to promote the use of humane alternatives when a person is in distress.

**The Gathering Place**

624 Doty St.

Green Bay, WI 54301

Telephone: (920) 430-9187

<http://www.dct.com/org/gathering/>

The Gathering Place is a 100 percent consumer-run center for all mental health consumers in the Green Bay area. Services/activities include: Bridges education course; monthly meal planning and preparation; monthly speakers; computer skills classes/Internet access; expressive art therapy; educational videos; Packers tailgate parties.

**Harm Reduction Coalition**

22 W. 27th St., 9th Floor

New York, NY 10001

Telephone: (212) 213-6376

Fax: (212) 213-6582

*and*

3223 Lakeshore Ave.

Oakland, CA 94610

Telephone: (510) 444-6969

Fax: (510) 444-6977

<http://www.harmreduction.org/>

This organization fosters alternative models to conventional health and human services and drug treatment, challenges traditional client/provider relationships, and provides resources, educational materials, and support to health professionals and drug users in their communities to address drug-related harm.

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**Iowa Mental Health Recovery and Advocacy**

P.O. Box 410

Woodward, IA 50276-0410

Telephone: (800) 775-2379

(515) 438-2028

<http://www.angelfire.com/biz/iowacoalition/>

Founded by consumers of mental health services, this coalition promotes self-help and assistance in areas such as education, employment, housing, and mental health services. Services include a peer support specialists program that offers people training to provide telephone wellness checks, home visits, transportation, and linkage with community resources to decrease the rate of hospitalization and crisis situations. This group also publishes a monthly newsletter.

**Justice In Mental Health Organization (JIMHO)**

421 Seymour

Lansing, MI 48933

Telephone: (517) 371-2794

(800) 831-8035

<http://hometown.aol.com/jimhofw/>

JIMHO is a nonprofit organization founded in 1980 run by individuals who are, or have been, consumers of the public and/or private mental health system, as well as an advocacy group and mutual self-help organization offering a network of support. Oversees Project Stay, which started as five drop-in centers providing a supportive network for consumers/survivors in the community. There are now 25 affiliated drop-in centers throughout Michigan.

**M-POWER**

Massachusetts People/Patients Organized for Wellness Empowerment and Rights

197 Ashmont St.

Dorchester, MA 02124-3801

Telephone: (617) 929-4111

<http://www.m-power.org/>

A member-run organization of mental health consumers and ex-patients, advocating for political and social change within the mental health system and the community, city and statewide. Offers jobs with stipends to consumers. Received grants within the last year (1999) to engage in grassroots organizing, leadership development and training.

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**MadNation**

4386 W. Pine Blvd., One East  
St. Louis, MO 63108  
Telephone: (314) 652-0424  
Fax: (661) 791-7058  
<http://www.madnation.org/>

MadNation is an organization working for social justice and human rights in mental health. Since its establishment by St. Louis activist Vicki Fox Wieselthier in late 1997, over 800 people have joined MadNation and contributed to its success. The MadNation website is visited by over 5,000 people a month.

**Mental Health Consumer Concerns, Inc. (MHCC)**

1420 Willow Pass Road, Suite 120  
Concord, CA 94520  
Telephone: (925) 646-5788  
Fax: (925) 646-5787  
<http://aesir.damerica.net/~mhcc/>

MHCC is a nonprofit organization founded and run by and for consumers of the mental health system. Administers patients' rights advocacy and training programs, the Contra Costa Network of Mental Health Clients, the Office for Family Involvement and Consumer Empowerment (O.F.F.I.C.E.), the Tender Loving Care Project, the Napa Self-Help Program, the Martinez, Concord and Pittsburg Community Centers, and the Warm-Line. MHCC also provides peer counselors for the Supported Housing/ACCESS program and the Health, Housing & Integrated Services Network. In 1981, MHCC was awarded the Patients' Rights Advocacy contract in Contra Costa County. This was the first Patients' Rights Advocacy contract in California to be awarded to a group of ex-mental health clients.

**mentalhealthconsumers.org**

<http://www.mentalhealthconsumers.org/>

An umbrella site for several Cincinnati-based mental health organizations, including:

**Mental Health Consumer Network, Inc.**

2601 Melrose Ave., Suite 302  
Cincinnati, OH 45206  
Telephone: (513) 221-7755  
<http://www.mentalhealthconsumers.org/connet/index.htm>

A nonprofit organization providing a warm-line, a consumer network group leader/community liaison who does outreach to consumers about consumer empowerment and consumer network programs, and *Consumer Network News*, a newsletter.



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**Recovery Initiative**

2601 Melrose Ave., B-100

Cincinnati, OH 45206

Telephone: (513) 221-8660

<http://www.mentalhealthconsumers.org/recovery/index.htm>

Operated and staffed entirely by consumers, this organization's services include a resource center providing peer support, and community education that focuses on basic computer instructions and other technology services such as consumer e-mail, Internet connection, fax services, electronic housing referrals, computerized job referral system, keyboarding skills and word processing. Also includes "Vulcan's Forge," a consumer art group supporting consumers' artistic endeavors.

**Mental Health Consumer Initiative**

P.O. Box 291

Danvers, MA 01923

Telephone: (800) 731-2299

(508) 898-3144

<http://www.kersur.net/~mhci/>

This consumer advocacy organization provides the following services: information on mental health and legal resources; coalitions of consumer groups and professionals to enact legislation to protect mental health consumers; dissemination of information to consumers on current mental health issues through newsletter, *Mental Notes*; works with representatives of the media to publicize problems and abuses in the mental health system; and organizes educational forums for mental health consumers.

**National Association for Rights Protection and Advocacy (NARPA)**

P.O. Box 4664

Lawrence, KS 66046-1661

Telephone: (785) 838-3836

<http://www.connix.com/~narpa/>

An independent organization that exists to expose everyday abuses in mental institutions.

**National Empowerment Center**

20 Ballard Road

Lawrence, MA 01843

Telephone: 1-800-POWER-2-U

<http://www.concentric.net/~Power2u/>

A consumer-run organization providing networking and coalition building, a national directory of mutual support groups, drop-in centers and statewide organizations, and education and training to providers from a consumer/survivor perspective.

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**Office of Consumer Technical Assistance (OCTA) of Oregon**

1528 S.E. Holgate

Portland, OR 97202

Telephone: (503) 231-3052

(888) 790-9379

Fax: (503) 231-1949

<http://www.orocta.org/>

OCTA is a statewide consumer-run organization that provides technical assistance to help consumer-run activities and to involve consumers in existing mental health services. Also, the following website has a long list of consumer/survivor-run organizations in Oregon, describing what each does, locations, etc.:

[http://www.orocta.org/consumer\\_run\\_organizations.htm](http://www.orocta.org/consumer_run_organizations.htm)

**Oakland Independence Support Center (OISC)**

580 18th St.

Oakland, CA 94612

Telephone: (510) 281-7705 (administration)

(510) 281-7700 (services)

Fax: (510) 281-7725

<http://www.sirius.com/~oisc/>

A self-help, client-run organization in downtown Oakland, OISC was founded by Howie the Harp and other consumer/survivors. It provides a network of services and peer support for the psychiatrically-disabled homeless, near homeless, and “multi-diagnosed” population.

**Peer Center**

4545 N.W. 9th Ave.

Fort Lauderdale, FL 33309

Telephone: (954) 202-7379

<http://www.peercenter.org/>

The Peer Center is a nonprofit advocacy and support center for mental health consumers. It is a completely consumer-operated program, in which both staff and members have experienced mental illness, and owns a building complex in Fort Lauderdale where it operates a drop-in center. Its website has an extensive, up-to-date activities calendar. The Peer Center also operates a program located on the grounds of Atlantic Shores/South Florida State Hospital called:

**Forest Park Drop-In Center**, which provides services to inpatients, referrals to other consumer-run groups, and support after release from the hospital. Recently, this group provided training to the hospital staff of Forest Park in peer advocacy, and now the staff provide advocacy for the residents six days a week.

The Forest Park Drop-In Center

1000 S.W. 84th Ave.

Pembroke Pines, FL 33025

Telephone: (954) 967-7900

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**People Against Coercive Treatment**

Toronto, Ontario, Canada

Telephone: (416) 760-2795

Fax: (416) 368-5984

<http://www.tao.ca/~pact/>

A grassroots organization of psychiatric survivors who are active in advocacy activities.

**Ruby Rogers Advocacy and Drop-In Center**

One Davis Square, Suite 207

Somerville, MA 02144

Telephone: (617) 625-9933

Fax: (617) 625-8374

<http://www.m-power.org/ruby.html>

For self-help, socializing, and advocacy. Run by and for ex-patients during the last 10 years.

**SAFE**

230 Main St.

Springfield, OR 97477

<http://www.efn.org/~safe/>

A nonprofit organization owned and operated by current and former consumers of mental health services in Lane County.

**Stepping Stone Peer Support and Respite Center**

188 Broad St.

P.O. Box 684

Claremont, NH 03743

Telephone: (603) 543-1388

**Next Step Peer Support**

56 Bank St.

Lebanon, NH 03766

Telephone: (603) 448-6941

This organization offers crisis intervention and respite services for consumers/survivors, run and operated by consumers/survivors, and based on principles of mutuality. It provides week-long training on issues of boundaries, noncoercive interventions, and developing mutual relationships.

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**Support Coalition International**

454 Willamette, Suite 216  
P.O. Box 11284  
Eugene, OR 97440-3484  
Telephone: (541) 345-9106  
Fax: (541) 345-3737  
<http://www.MindFreedom.org/>

This organization provides information on human rights campaigns involving stopping force and fraud in electroshock, and stopping forced outpatient drugging. They publish the newspaper *Dendron*.

**Texas Mental Health Consumers**

7701 North Lamar, Suite 500  
Austin, TX 78752  
Telephone: (512) 451-3191  
(800) 860-6057  
Fax: (512) 451-8302  
<http://www.tmhc.org/>

This is a statewide coalition of proactive consumer leaders from throughout Texas. The mission of Texas Mental Health Consumers is to encourage, educate, train, and organize people who have received services, voluntarily or involuntarily, from the mental health system to advocate for themselves and to support each other.

**United Self-Help**

277 Ohua Ave.  
Honolulu, HI 96815  
Telephone: (808) 926-0466  
Fax: (808) 926-1651  
<http://www.pixi.com/~ush/>

This is a consumer-run, nonprofit organization providing support groups and other services that help improve the quality of life for consumers.

**West Virginia Mental Health Consumers Association**

1036 Quarrier St., Suite 208A  
Charleston, WV 25301  
Telephone: (304) 345-7312  
(800) 598-8847  
Fax: (304) 345-7303  
<http://www.contac.org/WVMHCA/>

This is a nonprofit agency created to organize a mental health consumer network throughout West Virginia. It provides information on consumer service centers, a warm-line, and information on consumer rights and protection.

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## Other Sites of Interest on the Internet

### **Consumers as an Alternative Labor Pool**

<http://www.ccc-international.org/conswork.htm>

This report, written by Beth Stoneking, L.C.S.W., is about a project that began April 1990 in Sacramento County to integrate consumers through employment in case management, self-help, and other community organizations. It addresses: planning, recruitment, training, and selection strategies used; the accommodations and supports provided to consumer case managers; and the Human Resource Development “RIGHTS” related to employing consumers.

### **IndependenceFirst**

600 West Virginia, Suite 301  
Milwaukee, WI 53204-1516  
Telephone: (414) 291-7520  
Fax: (414) 291-7525  
<http://www.independencefirst.org/>

A nonresidential independent living center, IndependenceFirst is run primarily by people with disabilities, providing peer counseling, advocacy, and resources.

### **KEN — Knowledge Exchange Network**

P.O. Box 42490  
Washington, DC 20015  
Telephone: (800) 789-2647  
(301) 443-9006 (TDD)  
Fax: (301) 984-8796  
<http://www.mentalhealth.org/>

Developed by the Center for Mental Health Services, KEN provides information for users of mental health services and their families, the general public, policymakers, providers, and the media.

### **The Milwaukee Women’s Center, Inc.**

611 North Broadway, Suite 230  
Milwaukee, WI 53202  
Telephone: (414) 272-6199  
Fax: (414) 272-0757  
<http://www.mincava.umn.edu/mwc/index.html>

A woman- and minority-governed, nonprofit organization, the Center’s services include a 24-hour crisis line and a women’s refuge. It was started as a crisis line and shelter for women who were being abused by their partners.

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**Missouri Institute of Mental Health**  
**The Program in Consumer Studies and Training**

5400 Arsenal St.  
St. Louis, MO 63139  
Telephone: (314) 644-7829  
Fax: (314) 644-7934  
<http://www.cstprogram.org/>

This eight-site knowledge development program is designed to evaluate the extent to which consumer-operated services are effective in improving the outcomes of adults with serious mental illness when used as an adjunct to traditional mental health services.

**National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA)**  
<http://www.nasmhpd.org/consurdiv.htm>

This organization represents state mental health department senior managers who are current or former recipients of mental health services. It offers technical assistance to state mental health departments who are interested in creating offices of consumer/ex-patient relations.

**National Clearinghouse on Alcohol and Drug Information (NCADI)**  
Telephone: (800) 729-6686  
<http://www.health.org/>

A service of SAMHSA, this is the world's largest resource for current information and materials concerning substance abuse.

**National Mental Health Association (NMHA)**  
1021 Prince St.  
Alexandria, VA 22314-2971  
Telephone: (703) 837-4788  
(703) 684-7722  
Fax: (703) 684-5968  
<http://www.nmha.org/>

NMHA is an organization that works to improve mental health services, educates about mental illnesses, and promotes mental health. It is working for parity of mental health benefits from insurance companies and collaborated with the federally-supported National GAINS Center for People with Co-Occurring Disorders in the Justice System to produce the Justice for Juveniles Initiative.

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## **Peer Specialist Demonstration Project**

The New York State Office of Mental Health (NYOMH) has developed civil service (G-9) positions for peer specialists as part of its program development activities in the Pre-Paid Mental Health Plan (PMHP). Peer specialists are hired to work at selected PMHP sites across the state to ensure “full implementation of Self-help and Empowerment services which are a required part of the benefit package” (pg. 1). The project is coordinated by the Office of Mental Health Bureau of Recipient Affairs and includes training, technical assistance and other support services to PMHP sites. The Pre-Paid Mental Health Plan, Peer Specialist Demonstration Project: Information for Facilities (*New York State Office of Mental Health, October 1997*) provides excellent guidance for individuals attempting to develop positions for people who have received publicly funded services. More information is available from:

Darby Penney, Director of Recipient Affairs  
New York State Office of Mental Health  
44 Holland Ave.  
Albany, NY  
Telephone: (518) 473-6579

### **The Sidran Foundation**

2328 West Joppa Road, Suite 15  
Lutherville, MD 21093  
Telephone: (410) 825-8888  
<http://www.sidran.org/>

A nonprofit organization that works for support of people with psychiatric disabilities, The Sidran Foundation develops programs and publications for survivors of trauma.

### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

<http://www.samhsa.gov/>  
U.S. Health and Human Services Agency  
[http://www.samhsa.gov/mc/qtr\\_guide/consumersrole/refguide.htm](http://www.samhsa.gov/mc/qtr_guide/consumersrole/refguide.htm)

This is an excellent overview of the roles consumers of substance abuse and mental health services, families and advocates can play in the process of contracting for public-sector managed care.

### **Wisconsin Coalition Against Sexual Assault**

123 East Main St.  
Madison, WI 53703  
Telephone: (608) 257-1516  
Fax: (608) 257-2150  
<http://www.wcasa.org/>

This statewide network promotes social change to end sexual violence in Wisconsin by providing a resource library, training, publications, and policy development.

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**Wisconsin Coalition for Advocacy**

16 North Carroll St., Suite 400

Madison, WI 53703

Telephone: (608) 267-0214

Fax: (608) 267-0368

<http://www.law.wisc.edu/wca/>

This is the state's protection and advocacy agency for people with developmental disabilities, serious mental illness, or physical/sensory disabilities.

**Information About Free and Low-Cost Computers and Internet Access**

- <http://www.peoplepc.com/index.htm>  
For \$24.95 a month, you get a high-quality, name-brand, new computer, replaced every three years, with unlimited Internet access. Sign up for 3 years.
- <http://www.getyourfreepc.com/index.html>  
A free personal computer every 3 years.
- <http://www.isps.8m.com/freepcs.htm>  
List of free computer offers.
- <http://www.isps.8m.com/freeisp.htm>  
List of places offering free Internet access.

**Addresses of Groups Without Internet Addresses****Mental Health Empowerment Project, Inc.**

261 Central Ave.

Albany, NY 12206

Telephone: (518) 434-1393

(800)-MHEPINC

Fax: (518) 434-3823

This organization is connected to more than 500 self-help groups that they helped start.

**Mentality**

1024 Hill St.

Ann Arbor, MI 48109-3310

Telephone: (734) 936-2437

Fax: (734) 647-7464



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## Appendix III: Study Sites, Coordinating Center and Federal Project Officers

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### Women, Co-Occurring Disorders and Violence Study Sites

#### **Culver City, California — PROTOTYPES**

##### **PROTOTYPES Systems Change Center**

PROTOTYPES, Children and Family Futures (CFF), and Human Interaction Research Institute (HIRI), will develop and implement an integrated system of care for women with co-occurring disorders who are victims of violence and for their children. The Center will use a “Readiness for Change” model in the implementation of an integrated services system. Based on this model, three components will be established: integrated services; system-wide training; and planning and coordination at the county level.

#### **Stockton, California — ETR Associates, Inc.**

##### **Allies: An Integrated System of Care**

Education Training Research (ETR) Associates and San Joaquin County’s Health Care Services will develop and implement an integrated services care system, referred to as “Allies,” with ETR serving as the lead agency. The structures that Allies will utilize are a Coordinating Council (including consumer/recovering individuals), an expanding group of Core Service Agency Providers working in partnership, and an intensive multidisciplinary Case Management Team.

#### **Thornton, Colorado — Arapahoe House, Inc.**

##### **New Directions for Families**

Through its New Directions for Families project, Arapahoe House will refine and document its intervention for women victims of violence with co-occurring substance abuse dependence and mental health disorders, as well as their children. The program’s services currently include: comprehensive assessment; health services; integrated substance abuse and mental health treatment; specialized women’s groups; parenting skills classes; family activities; education and vocational services; and linkage to a variety of community resources. Arapahoe House will add direct outreach focused on identifying and engaging in treatment women victims of violence, and additional services for women victims, as well as their children who are victimized or witness violence.

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## **Washington, DC — Community Connections**

### **District of Columbia Trauma Collaboration Study**

The DC Trauma Collaboration Study will establish a Trauma Center as the central mechanism for developing an integrated system of care more responsive to the needs of women with co-occurring mental health and substance abuse disorders who have been victims of violence and to the needs of their children. Community Connections, the lead agency, will partner with a research team from the New Hampshire-Dartmouth Psychiatric Research Center to implement and evaluate a full range of service systems integration activities designed to enhance the coordination, accessibility and effectiveness of mental health, substance abuse, and trauma (MHSAT) services. The key integration activities of the Center will be: education; outreach and identification; coordinated referral; services integration; and advocacy.

## **Avon Park, Florida — Florida Center for Addictions and Dual Disorders**

### **Triad Women's Project**

The Triad Women's Project is designed to improve the lives of women and their children in a rural district in Central Florida by facilitating survival from abuse and violence, empowerment in coping with psychiatric disorders, and recovery from substance abuse disorders, while describing and evaluating all interventions contributions to this improvement. Tri-County Human Services, Inc. (TCHS) will work with the Louis de la Parte Florida Mental Health Institute (FMHI) to strengthen collaborations of service providers, consumers/survivors, and community members. A thorough needs assessment will be conducted and as the collaboration is developed, the dynamics of change will be documented qualitatively and quantitatively.

## **Miami, Florida — University of Miami**

### **Safe Life: A Study of Abuse Among HIV-Infected Women and Their Children**

Through the Safe Life program, the University of Miami Department of Psychiatry and Behavioral Sciences will plan, deliver and evaluate an integrated system of care with a proposed services intervention model for women with co-occurring histories of physical and/or sexual abuse and alcohol, drug abuse, or mental disorders. The targeted population is HIV-infected women and their children in Miami. Safe Life will employ formative, process/implementation, and outcome evaluation approaches to determine the effectiveness of the project.

## **Baltimore, Maryland — Maryland Department of Mental Health and Mental Hygiene**

### **TAMAR Project**

The TAMAR (Trauma, Addictions, Mental Health and Recovery) Project will target adult women with alcohol, drug abuse, mental health (ADM) disorders and histories of violence who are currently inmates in detention centers for misdemeanors or nonviolent felony offenses. The project includes several components: a formal interagency agreement linking local service organizations; interagency meetings among frontline staff; training on trauma issues for mental health, substance abuse, correctional, social services and parole and probation staff; intensive case management; a state director of trauma services and a state clinician to supervise; and connection to specialized services for the women and their children.

## **Boston, Massachusetts — Boston Public Health Commission**

### **Boston Consortium of Services for Families in Recovery**

The Boston Public Health Commission (BPHC) will develop and implement a model for a city-based integrated system of services for poor, inner-city, culturally-diverse women with alcohol and/or drug addiction and co-occurring mental health disorders who have a history of physical and/or sexual abuse, as well as for their children. The project will develop and implement intervention models lacking in the current system, and test the effectiveness of the model based on: outcomes of the women; outcomes of the children; changes in the system of care; consumer participation; and cost effectiveness.

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**Cambridge, Massachusetts — Institute for Health and Recovery**  
**The Women Embracing Life and Living (W.E.L.L.) Project**

The Institute for Health and Recovery (IHR) — in collaboration with CAB Health and Recovery Services, Gosnold, and Stanley Street Treatment Resources — will develop a two-tiered approach to systems and service integration for women with co-occurring disorders who have experienced violence, along with their children. This two-tiered approach includes statewide, as well as local, interventions. Several service interventions will be developed: integrated care facilitation; client screening and assessment tools; specific trauma services; client service mapping protocols; integrated cross-training curriculum of substance abuse, mental health and violence; expansion of the IHR Nurturing Program; and community support services.

**Greenfield, Massachusetts — Western Massachusetts Training Consortium, Inc.**  
**Franklin County Women and Violence Project**

The Franklin County Women and Violence Project (FCWVP) is a collaborative endeavor by the Human Resource Association of the Northeast (a program of the Western Massachusetts Training Consortium, Inc.), in partnership with the New England Learning Center for Women in Transition (NELCWIT), Franklin Medical Center and Rutgers University. FCWVP's mission is to develop an integrated system that supports and enhances the lives of women in the greater Franklin County area who have co-occurring mental health and substance abuse disorders and histories of trauma. The services also will be provided for their children. FCWVP intends to focus on: direct services provision; improved access to care; improved services coordination; and enhanced individual and community capacities.

**Joplin, Missouri — Lafayette House**  
**Integrated Services for Women and Children in the Ozarks**

The Missouri Division of Alcohol and Drug Abuse and the Family Self Help Center's Lafayette House will establish a collaborative agreement to provide an integrated services system for women who suffer from substance abuse and mental illnesses, and who have been victims of violence. The services also will be provided for their children. The program's goals include: establishment of a local Coordinating Council; refinement of the preliminary needs assessment; definition of core elements of an integrated system; establishment of policies and procedures; development of standardized forms; training of staff and provider agencies; establishment of interagency case management teams; and development of services to ensure core elements of an integrated system.

**New York, New York — Project Return Foundation, Inc.**  
**Portal Project**

Project Return Foundation will collaborate with Dr. Andrea Savage and her evaluation team from the Hunter College School of Social Work to study 200 women, and their children, who are high-end users with co-occurring issues of substance abuse and mental illness, and who have been victims of violence. PRF seeks to: build an integrated system of attention and care through a Project Advisory Committee composed of key stakeholder service providers, communities and consumers; develop a comprehensive assessment and consumer-driven service model that can be tailored to the targeted population; and create multidisciplinary, multi-stakeholder team case conferences to explore the interaction of substance abuse, mental illness and multiple forms of violence against women.

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## **Portland, Oregon — Project Network Kuumba Project**

Kuumba, Swahili for “creativity,” will develop an integrated services model for women with co-occurring substance abuse and mental health disorders who are victims of physical and/or sexual abuse, as well as for their children. Project Network, a program of Legacy Health System, will implement the Kuumba Project in conjunction with local service providers and the Regional Research Institute for Human Services of Portland State University. Services to women and their children in the project will include: a comprehensive assessment; multi-organizational service planning involving the consumer, family members and community supports; services at the least restrictive level and by the most acceptable and accessible organization; and the development of individualized supports to meet their needs. The mental health, alcohol and drug, and trauma treatment will be provided at a single site with the consumer as an integral part of the treatment and healing. Additionally, a strong alumni group and client council will be involved in all levels of planning and service.

## **Madison, Wisconsin — University of Wisconsin–Madison The Women and Mental Health Project of Dane County**

The major goal of this project is to affect changes in the various service delivery systems, and their provider organizations, so that women in Dane County who have mental health and substance abuse problems and histories of abuse or violence can receive services that adequately address their needs and those of their children. The project will initiate: needs assessment, which will assess the number of women receiving services in the public sector who meet the study criteria and evaluate the scope and nature of their needs and quality of their care; systems change activities, which will engage consumers, providers and community stakeholders in a process aimed at determining the nature of the target population’s unmet needs, and available options for changing the services and systems to meet those needs; system change assessment, which will focus on the changing communication networks among principal service providers and the role of boundary spanners within service providers.

## **Coordinating Center**

### **Women, Co-Occurring Disorders and Violence Coordinating Center**

Policy Research Associates, Inc.

345 Delaware Avenue

Delmar, NY 12054

Phone: (518) 439–7415

Fax: (518) 439–7612

E-mail: [wvcc@prainc.com](mailto:wvcc@prainc.com)

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## **Federal Project Officers**

### **CDR Melissa Rael, RN, BSN, MPA**

Systems Development and Integration Branch  
Center for Substance Abuse Treatment  
Substance Abuse and Mental Health Services Administration

### **Jeanette Bevet-Mills, M.Ed., MS**

Division of Knowledge Development and Evaluation  
Center for Substance Abuse Prevention  
Substance Abuse and Mental Health Services Administration

### **Susan Salasin**

Community Supports Programs  
Center for Mental Health Services  
Substance Abuse and Mental Health Services Administration

## **The Women Co-Occurring Disorders and Violence Coordinating Center**

Operated by  
**Policy Research Associates, Inc.**

The Women, Co-Occurring Disorders and Violence Study is generating knowledge on the development of integrated services approaches for women with co-occurring mental health and substance abuse disorders who also have histories of physical and/or sexual abuse.

This report is a product of the Women, Co-Occurring Disorders and Violence Study Coordinating Center, which is operated by Policy Research Associates in partnership with The Better Homes Fund, and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina, Chapel Hill. The Coordinating Center provides technical assistance to program sites, conducts cross-site process and outcome evaluations, and develops a range of application products from the study sites.

The Women, Co-Occurring Disorders and Violence Study is funded by the Substance Abuse and Mental Health Services Administration's three centers – The Center for Substance Abuse Treatment, The Center for Substance Abuse Prevention, and the Center for Mental Health Services.

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*For more information on this initiative, please contact:*

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